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ABSTRACT

The directory is intended to aid patients and their families who are coping with the genetic disorder of Cooley's anemia. A brief review of the disease covers background, genetics, symptoms, effect on the patient, treatment, and current research. The next section looks at psychosocial needs at various times (time of diagnosis, infancy and toddler years, preschool years, school years, adolescence, and young adulthood). The next section describes resources in the following areas: medical care and management, genetic services, self-help and advocacy groups, education, employment, financial assistance, medical assistance, transportation, civil rights/legal assistance, tax benefits, and housing. Over half the document consists of appendixes including listings of: state genetic service coordinators, selected self-help and advocacy groups, state directors of maternal and child health and crippled children's services, state protection and advocacy programs. Also included are a selected reading list of 14 items and a glossary of 15 related terms. (DB)

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COOLEY'S ANEMIA: A PSYCHOSOCIAL DIRECTORY

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FOREWORD

This directory is primarily designed as an aid to patients and their families who are trying to cope with the genetic disorder known as Cooley's anemia. A brief description of current knowledge regarding the cause and management of Cooley's anemia (thalassemia) is included to clarify misunderstandings or misconceptions about the condition. An attempt has been made to outline some of the major problems individuals with Cooley's anemia and their families face and the type of help they may need. Suggestions on where and how the needed assistance might be obtained follow each section. The directory also lists state agencies, advocacy programs and self-help groups which can direct individuals and their families to an appropriate resource. In compiling these lists, the Division of Maternal and Child Health, the National Center for Education in Maternal and Child Health, the Cooley's Anemia Foundation, and the various consultants who contributed suggestions for this directory have functioned primarily as reporters. Inclusion of a resource in any of the listings does not constitute an endorsement; nor is it possible to evaluate individually the suggested resources in terms of their knowledge, experience with the condition, or the quality of their services.

Using this directory will help you locate the nearest appropriate agencies. Remember, not every service is available, and not every person can receive complete assistance. If you remain patient, probing, and realistic, we trust you will unearth useful information and make vital contacts.

Keep in mind that every year new programs begin and older ones dissolve, particularly at the state and local levels. Keep in touch with your contacts and stay aware of developments in the area of services for families and patients. Many excellent voluntary organizations, as well as state, local, and federal offices, can help you. Some of these produce newsletters, which can be used for maintaining your awareness of developments and changes in programs.

Cooley's anemia is not evenly or widely distributed throughout all communities. Many health care providers may not deal directly with the range of problems presented by patients with Cooley's anemia and their families. We hope that this directory will expose such health care providers to the problems presented, and orient them to the available resources. This effort should initiate an ongoing continuing education process for patients, families, and professionals.

Special acknowledgement is due to the ad hoc task group organized by the Division of Maternal and Child Health, BHDCA/PHS which with representatives of the Cooley's Anemia Foundation and federal agencies developed the initial approach and outline for this document.

A number of other people have been immensely helpful in providing valuable ideas, collecting and compiling information and for reviewing the manuscript in the different stages of its preparation. We are thankful to: Isabel Bailey, M.S.W., Children's Hospital, Boston, MA; Arthur Bank, M.D., Columbia Presbyterian Hospital, New York, NY; Nunzio Cazzetta, Vice President, Cooley's Anemia Foundation; Bas Chaudhary, M.D., National Executive Committee, Cooley's Anemia Foundation; Carmine F. Geonie, National Executive Committee, Cooley's Anemia Foundation; Haig Kazazian, M.D., Ph.D., Johns Hopkins University School of Medicine, Baltimore, MD; Jane Lin-Fu, M.D., Division of Maternal and Child Health, Rockville, MD; Dominique Sabatino, M.D., Long Island College Hospital, Brooklyn, NY; and Edward C. Zaino, M.D., Mercy Hospital, Rockville Center, NY.

Finally, gratitude must be expressed to the staff members of the National Center for Education in Maternal and Child Health for their combined efforts in the preparation of this directory: to Anna Hamilton for her inspirational leadership in assisting, coordinating, and motivating all of the various individuals involved in this publication; to the NCEMCH publications team, especially Kevin Bourke, Shawkat Hussain, and William Sybers for their painstaking job in editing and proofreading; and to Robert C. Baumiller, who, as the guiding force behind this enterprise, provided all with the necessary enthusiasm.

Michael DiFilippo, Executive Director
Cooley's Anemia Foundation

Rudolf P. Hormuth, Chairman
Ad Hoc Task Group
December 1985

COOLEY'S ANEMIA - A BRIEF REVIEW

Background

Cooley's anemia, Mediterranean anemia, and thalassemia major all refer to a severe, inherited form of anemia first described in 1925 by Dr. Thomas Benton Cooley, an American pediatrician. The first cases of this disorder were observed in persons from the Mediterranean region, hence the name Mediterranean anemia. It is now known that the range of this genetic disorder extends beyond the Mediterranean basin through the Middle and Far East. In the United States, most affected persons are descendants of families that originated from Italy and Greece. However, it is also encountered with significant frequency among persons of other origins, such as persons of Middle Eastern, Southeast Asian and African descent. Since the disease is not confined to persons from the Mediterranean region, the name Mediterranean anemia has been largely replaced by the less specific term thalassemia, which is derived from the Greek word "thalassa" or "sea". The basic defect in thalassemia is a decrease or absence of the synthesis of one or more of the globin chains of hemoglobin made by the body. Hemoglobin, the protein pigment of the red blood cells that carries oxygen to the tissues, is made up of heme, which contains iron, and four globin chains, of which there are at least four kinds, designated alpha, beta, gamma, and delta. There are several types of hemoglobin, determined by combinations of the four different kinds of globin chains.

In normal adults, 95-97 percent of the hemoglobin is adult hemoglobin (Hb A). Another hemoglobin, Hb A_2, comprises 1.5-3.5 percent of the total hemoglobin. Hb A has two alpha chains and two beta chains. Depending on the affected chain, thalassemia may be classified as alpha thalassemia or beta thalassemia.

Clinically, beta thalassemia is often divided into four groups, based on the severity of the manifestation. Thalassemia major refers to the severest form of the disease and is characterized by early onset of anemia and life-long dependency on blood transfusions. The term is used synonymously with Cooley's anemia. Thalassemia intermedia, also called mild Cooley's anemia, is characterized by moderate anemia which may or may not require transfusion. Thalassemia minor is an asymptomatic state which may or may not be associated with mild anemia but is characterized by certain changes in the red blood cells. Lastly, thalassemia minima is a totally silent state that cannot be detected with any certainty except by inference in genetic studies. Although clinical status cannot be used to define the genotype of a patient, persons with thalassemia major or Cooley's anemia are generally homozygous for beta thalassemia, and those with thalassemia minor or minima are heterozygous for the thalassemia trait. Thalassemia intermedia can result from a variety of genetic disorders of beta chain synthesis. Because thalassemia is an extremely heterogeneous group of blood disorders, there are exceptions to the above-stated generalities.

Although the carrier state of beta thalassemia is compatible with an entirely normal life, such persons usually demonstrate an increased level of Hb A_2 and a varying degree of abnormalities in their red blood cells.

Genetics

Cooley's anemia may be inherited if both parents carry the gene for thalassemia. If each parent has thalassemia trait, there is a one-in-four chance with each pregnancy that the child will have Cooley's anemia, a one-in-two chance that the child will have the trait, and a one-in-four chance that the child will not carry the trait. Because these chances also apply for each succeeding pregnancy, each offspring has the same chance of inheriting the disorder.

If only one parent has beta thalassemia trait, each child born will have a one-in-two chance of having the trait. Cooley's anemia can occur only if both parents are carriers. Risk factors can be further explained by a genetic counselor.

Symptoms

The earliest signs include paleness, weakness, irritability, and failure to thrive. Fever, feeding problems, diarrhea, and other gastrointestinal symptoms may also be present. An infant with Cooley's anemia appears healthy at birth. Signs of the disease first develop a few months after birth and become progressively more severe. Early identification, important in treating thalassemia, now includes prenatal diagnosis of the disorder. Prenatal diagnosis is possible at 16 weeks of pregnancy with amniocentesis. A new experimental procedure, chorionic villus biopsy, is available at some major medical centers. This technique can be done at 8 to 10 weeks of pregnancy.

Effect on the Patient

Because the defective red blood cells do not contain enough hemoglobin, children with Cooley's anemia face complicated clinical problems. The fragile red blood cells break down within a few weeks instead of lasting four months, the lifetime of normal red blood cells.

If the disease is left untreated or inadequately treated, the need for new red blood cells to replace damaged cells causes the bone marrow cavity, where the cells are made, to expand remarkably. As the bone marrow spaces widen, the bones become thinner and fracture easily. Because of this, children with Cooley's anemia who have not received adequate transfusions can sometimes have a characteristic appearance, with prominent cheek bones, slanting eyes, overgrowth of the upper jaw, jumbled upper teeth, and an overbite due to expansion of the bone marrow cavities of the skull and face. Fortunately the use of deferoxamine, an iron chelator, has allowed for more frequent transfusions, producing stronger bones and practically normal facial appearance.

As red blood cells break down, their components become waste products and are eliminated through a process occurring mainly in the spleen and liver. The accelerated breakdown of red blood cells in Cooley's anemia produces more work for these organs. Consequently, they become oversized and often do not function properly. Although enormous in size, the spleen may fail in its critical function of protecting the body against infection. Enlargement of the spleen also leads to a condition called hypersplenism, in which the destructive process in the spleen is exaggerated, resulting in the premature breakdown of platelets, white blood cells, and transfused (normal) red blood cells.

The iron released from the accelerated destruction of red blood cells remains in the body and is deposited in all the tissues, especially the heart, liver, endocrine glands, and skin. Excess iron, or iron overload, in the heart and liver interferes with the functions of these organs. Excess iron in the endocrine glands can cause diabetes mellitus, calcium deficiency, poor thyroid function, and impairment of sexual function.

Growth tends to be slower than normal. With early diagnosis and newer forms of treatment, however, children with Cooley's anemia are able to grow more normally, and do not have the typical facies of inadequately treated children.

Treatment

Without treatment, the victims of Cooley's anemia die in early childhood, usually as a result of overwhelming infection. Although blood transfusions may be used to treat the symptoms of anemia, patients who receive only blood transfusions eventually die from complications caused by deposits of excess iron in the heart muscle. However, a combination of blood transfusions and a chemical "iron chelator" to remove excess iron has extended life expectancy into the early twenties. Treatment is started at the time of early diagnosis. The quality of life for these patients has greatly improved since the introduction of modern therapy, but life expectancy of patients who are treated from early infancy is at present unclear, since such therapy represents a recent medical advance.

The transfusions of packed red blood cells, used to relieve the anemia and its effects, diminish the overactive production of red blood cells by the bone marrow. The storage of iron in vital organs that results from repeated transfusions constitutes a serious side effect. As mentioned above, this can be prevented by utilizing transfusions with an iron chelator, such as deferoxamine, which combines with the iron and helps remove it through the excretory system. Treatment with deferoxamine seems to have remarkably few side effects when injected under the skin.

Research

Scientific research on Cooley's anemia and similar genetic diseases is sponsored by the National Heart, Lung, and Blood Institute; the National Institute of Arthritis, Metabolism, and Digestive Diseases; the National Institute of General Medical Sciences; and other Institutes of the National Institutes of Health, as well as by a number of voluntary organizations. Important in basic research are studies of the genes and how they function. Current clinical research aims to improve techniques for transfusions and iron chelation therapy. In the laboratory, researchers are examining bone marrow transplantation as a possible treatment for Cooley's anemia. In addition, as we learn more about the molecular basis of the disorder, the possibility of gene therapy holds much promise as a means of effective treatment.

The Diagnosis

Some parents suspect that their baby may have problems before or shortly after birth. Other parents may not be aware of this possibility until certain physical signs begin to appear in the first few months. No matter how carefully and sensitively the health care provider conveys a diagnosis of Cooley's anemia, the process of receiving and coping with such information represents a devastating event for all parents.

Most expectant families invest dreams and hopes in the coming child. A diagnosis of Cooley's anemia can change these aspirations, dramatically altering the family's view of their baby and themselves. Questions such as, "Why did this happen to us?" and "What did we do wrong?" naturally emerge. Even the ray of hope offered by management and treatment help is tempered by the ultimate realization of the need for complicated, life-long care.

While the health care professionals involved can provide a measure of reassurance by outlining a management program and lifetime goals, the family members themselves must put the pieces together, heal the trauma, and cope with the anxiety, guilt, and recriminations. They must live with the questions of "What kind of a person will this baby be?" and "How can we manage all of this?"

Accepting the diagnosis and the absence of a cure represents an important first step in the healing process. This acceptance takes time and much more than a "one shot" explanation by the health care providers of what the family faces. Family life expectations need to be adjusted to make room for unanticipated demands. Extended counseling and explanations of the genetic aspects of the condition by the health care providers can relieve guilt and set the stage for translating what needs to be done into daily living practices. This step requires the support and understanding of relatives, neighbors, and religious advisors.

Meeting others facing similar problems can be the most important psychosocial support mechanism for many families. In realizing that they are not alone, families share feelings, frustrations, concerns and successes with others. Health care providers can occasionally provide access to other families during clinic or hospital visits. Family discussion groups can also contribute to comprehensive management. Joining self-help and advocacy groups and maintaining such contacts on an ongoing basis can provide even more effective support. Participation in organized efforts to increase community awareness of the problem, to stimulate better care and treatment, and to support the search for a cure, permits these families to help themselves and others deal more effectively with the many problems they face.

Infancy and the Toddler Years

Many parents, after being told that their baby has a problem such as Cooley's anemia, become so upset that they temporarily forget all they know about babies and their care. An attitude of "Why bother? Where will all this lead?" in the initial period following the diagnosis reflects a request for help and support.

Support for the parents and family from relatives, friends, church, advocacy, and parent groups can be of major assistance at this point. Professional counseling may enable the family to openly admit that they have a problem, and to accept the support of relatives and friends.

In the care of all babies, good health is a priority. The success of any special treatment depends on a good health status. In cooperation with the family, the doctor or pediatrician plans a program to nourish the child, prevent illness, correct defects and promote growth and development. Family participation in this health care plan provides an element of support.

While chronic conditions can affect a baby's development, parents should remember that their baby is more normal than abnormal. Positive attitudes in the home can help develop a good, wholesome personality. A strong feeling of "I belong" is crucial as babies begin to reach out to parents, siblings and the extended family. All those individuals involved with the child's care have rights to privacy, recreation, and relief. If families honor these rights, no one member will feel overburdened, and a positive attitude in the home can be reinforced.

The Preschool Years

Parents can, to a large degree, control an infant's early behavior. Dangerous and undesirable objects can be put out of reach, and a protective and nurturing environment can be built around the child. As the toddler begins to explore, protection becomes more difficult to ensure, and parents must allow the child to learn that certain behavior is acceptable, while other behavior is not. This learning and judgment comes from practice in making decisions and depends on the extent to which families are prepared to let go of some of their concerns for protection and permit exposure to new experiences, both in and outside of the home.

Exposure to situations and people outside of the home can help to set the stage for the many trips to clinics and hospitals for medical care and management. The beginning of more intensive medical treatment frequently coincides with a stage of development in which the child might ask "Will it hurt for long?" "Why do we have to go?" At this point, the child needs to trust in what he or she is told. Added support from members of the health care team can assist parents to effectively deal with this stage.

The use of a more formal kind of community resource like a Sunday school or play group can be effective in preparing a child for a nursery school or day care experience. Use of these resources can prepare the child more adequately for a successful school experience and, to a limited extent, provide a measure of relief for the parents while the child is out of the home. Parents can expect questions and concern from some of these preschool resources. Support from advocacy and/or parent groups and the health services provider team should be used to answer these concerns.

School Days

Going to school represents a milestone overshadowing all others in the mind of a child. It provides special opportunities and challenges, as well as some difficulties for the child affected with Cooley's anemia, the family and

the teacher. If the youngster has had a nursery or preschool experience, the adaptation to the school's routines and expectations should not be too difficult. The school and the teacher must be alerted to possible interruptions in the school routine for necessary medical care and management. Psychological characteristics which the child may have acquired often present more of a deterrent to adjusting to a full school program than any problem related to the medical condition. The ability to cope with the demands and expectations of the classroom should develop at home and in preschool groups. The flexibility required in the classroom may be something new to the youngster used to a rather rigid, inflexible management system. School entry mandates a considerable change in attitude by the family as well. At this time, the family must permit greater freedom, and permit exposure of the youngster to greater risks, a necessary part of growing up. If the family can make the transition, most youngsters can follow this lead. Teachers and school counselors can help structure these transitions with the family. The social worker or psychologist involved with the family can also offer assistance or refer to other resources, particularly if behavior problems emerge during these early school years.

School provides a range of new opportunities for friends, social experiences, and community activities both in and out of the classroom. The family encounters an added task of helping the child move more directly into the mainstream of life in the community. The success of this task depends partially on the example set by the family. If the family continues to mourn over the problem, remains withdrawn and fails to reestablish its social contacts, they can hardly expect the child to pursue a different pattern of daily living. The experience of moving out into the community stream of life should be introduced with family activities. Going to church, dining out, visiting friends or relatives, and family picnics with the child provide important learning experiences.

After-school activities, such as scouting, swimming, and interest groups expose the child to relaxed, open social environments. When not burdened by a completely structured schedule, the child receives the needed opportunity to "do nothing."

The family with a school-age child faces concerns about mounting medical costs and anxiety about the child's exposure to increased risks at this stage of development. Relief from the constant pressure of these demands and concerns is as vital to the family members as the school experience is to the child. Therefore, to maintain a stable and pleasant home environment, families must formulate plans to ensure periodic relief.

Adolescence

The need to belong and be with peers becomes an urgent priority during adolescence. For the adolescent with Cooley's anemia, however, this is also the time when the demands of medical treatment increase. Available leisure time is often replaced by more frequent medical appointments, and added attention to homework required to make up for missed school hours. Friendships established earlier may dissolve. In addition, peer groups grow more selective as to whom they will accept, and thus are they quicker to ostracize those whom they judge to be different.

Participation in extracurricular activities can provide adolescents with a sense of social value. However, adolescents with Cooley's anemia, when

excluded, often engage in solitary activities--they shoot baskets by themselves, they swim, they read. At times they may blame the family for their lonely and boring state.

Finding appropriate activities for these adolescents is a sizeable job. In most communities, no central agency exists to direct families to the right recreational or educational facility. While teachers and church groups can frequently help with suggestions, two obstacles remain--motivating the adolescent to participate and convincing the resource that the adolescent is capable of participating.

Siblings or cousins of a comparable age group can offer considerable help. Frequently more aware of resources, they can include the adolescent with Cooley's anemia in their activities and in their group. With a more acute awareness of Cooley's anemia and its impact, these adolescents can also benefit from an opportunity to spend time with people who have similar problems in "rap sessions." The medical center staff or the support group to which the family relates can help to arrange such group sessions.

The Young Adult

The young adult with Cooley's anemia has, to a large extent, beaten the odds of survival initially conveyed to the family when he or she was an infant. Experience has most likely molded a personality with a tremendous amount of determination. Unfortunately, the chronic dependency on medical care, the uncertainty of some aspects of the future, and the continuous realization that he or she is different from others of the same age, can make it difficult for these young adults to plan a future. However, many are attending college and have successfully secured a broad range of technical and professional positions such as secretaries, office personnel, and laboratory technicians.

Before seeking career or vocational help, these young adults should take stock of how they feel about themselves. Have all of their struggles been worthwhile? Are they ready to take on even more of a load? Do they feel good about what they have achieved? These questions need to be discussed, not only with adults with whom these individuals feel comfortable, but with other young adults facing the same future. For some, person-to-person discussions are easier. For others, the support of a group or a rap session with peers may be more effective.

Once this step has been taken, readily available resources can be used to help select career opportunities and provide prevocational experiences. What may be more difficult to find are the answers to questions generated by career preparation, and a support system to resolve these issues. These questions relate to independent living, mobility and economic independence, personal relationships, sex and marriage, and the successes and potential failures involved. These young adults are now expected to make decisions and find and use the support system that best suits their needs.

RESOURCES

MEDICAL CARE AND MANAGEMENT

A crucial ingredient in the medical care and management of individuals with Cooley's anemia involves the regular administration of red blood cells for life support. Appropriate management of this transfusion therapy requires a coordinated system of supports and services. A continuous supply of red blood cells must be assured at all times. In addition, the impact of the required therapy on the lifestyle of the individual and the family should be well managed. The iron accumulation that results from repeated transfusions must be monitored and treated, while iron chelation must be administered in ways least disruptive to activities of daily living. Cardiac disease and other common complications must be detected early and properly managed, and access to linked hospital care for acute medical emergencies must be available. A basic support system which assures coordination of and access to the necessary resources; quality control of laboratory tests, and active, informed participation by the patient, family, and community is necessary for successful care and management.

This complex network of services is generally beyond the capacity of an individual health care provider. It requires a team approach encompassing several disciplines, and resources usually available only at major medical centers. At a minimum, the coordinated skills and expertise of hematology, pediatrics or internal medicine, cardiology, endocrinology, psychiatry, psychology, social work, and nursing should be included. Most families of newly diagnosed Cooley's anemia patients are unfamiliar with existing resources and depend on referral to gain access to coordinated medical care and management. Families unable to obtain such referral services can turn to the following sources for information on the location, availability, and ways of accessing the medical care and management system nearest to where they reside.

GENETIC SERVICES

Individuals with Cooley's anemia and families concerned about the condition are well advised to take advantage of the current availability of genetic services throughout the country. In most states, these services operate as a part of the State Health Department Program of Maternal and Child Health, using a network of major medical centers and a series of local outreach clinics. With a multidisciplinary staff and comprehensive laboratory capability, genetic services centers can not only assist in screening procedures and confirmatory diagnosis, but have the experience, knowledge, and expertise to provide treatment, medical management, and counseling. These programs offer counseling to understand the hereditary process, the transmission of thalassemia, and the psychosocial component of the disorder on the affected individuals and family. Prenatal diagnosis is also avialable through these programs. Genetic services programs can be readily identified through your state's genetic service coordinator. A list of these individuals can be found in Appendix A. Comprehensive Clinical Genetic Services Centers: A National Directory 1985 is available from The National Center for Education in Maternal and Child Health, 38th and R Streets, N.W., Washington, DC 20057.

SELF-HELP AND ADVOCACY GROUPS

Before self-help and advocacy groups formally emerged, families searching for help in their attempt to deal with complicated and unusual conditions frequently encountered others engaged in similar searches. The assistance these families sought either did not exist or was not readily available. The need for mutual help and support was the primary motivation for organizing most of these groups.

Primarily focused on specific conditions, these groups serve as the principal means of calling attention to those conditions. They have exposed unmet needs, stimulated research, and supported the development of necessary special services.

These organizations and their local units provide information on specific conditions, available resources and services, state-of-the-art treatment, and management and research. Meeting other individuals who are facing or have faced similar problems can be a major source of support for those just beginning to face these problems. Many groups serve as advocates in assisting families to obtain services to which they are entitled. A number of these groups also sponsor or provide special psychosocial services for affected individuals. The support groups listed in Appendix B include those that are specifically focused on Cooley's anemia as well as a few groups that focus on a broad spectrum of problems related to chronic illness.

EDUCATION

The federal government, dedicated to the conviction that disabled persons possess the right to educational opportunities and services, provides assistance at many levels to enable children, youth, and adults to receive education and training.

Your Rights Under the Law

Under the provisions of the Education for All Handicapped Children Act of 1975 (P.L. 94-142), state and local school districts must provide an appropriate elementary and secondary education for disabled children from age 6 through 21. In those states mandating public education for children aged three to five, P.L. 94-142 requires that disabled children of that age group be educated in the least restrictive environment and, insofar as is appropriate, that they be educated with nondisabled children. This education must cost no more than it costs parents of nondisabled children.

All parents have the right to participate in the preparation of the individual education plan developed for their child. When state or local education systems place children in private schools in order to provide appropriate education, this must be done at no cost to the parent. Additional services such as transportation and special aids must also be provided at public expense.

Final responsibility for implementing the Education for All Handicapped Children Act rests with the state education agency. For further information on special education programs in your state or locality, contact the state, county, or local education offices.

Additional information on relevant sources of state assistance, the rights of disabled children and their parents, appeal procedures, and general advocacy information in the education field is available from:

National Information Center for Handicapped Children and Youth
P.O. Box 1492
Washington, DC 20013
(703) 522-3332

Head Start

Project Head Start, developed by state and local education systems with federal assistance, is a child development program providing comprehensive educational and social services, parent involvement, and health services (including medical, dental, nutrition and mental health services) to preschool children of low-income families. The 1972 Amendments to the Economic Opportunity Act call for at least 10 percent of the nationwide enrollment in Head Start to consist of disabled children and those who require special services.

For more information about eligibility and available Head Start programs in your area, contact your local school board or look under "Project Head Start" in the telephone directory.

Vocational Rehabilitation

All states offer vocational rehabilitation agencies that provide a wide range of services, financial assistance, and training, to help disabled persons become employable.

Expenses borne by the program will vary widely from case to case and state to state. Each state's resources are allocated according to state guidelines as well as recommendations of individual vocational rehabilitation counselors and administrators.

An individualized plan for rehabilitation is formulated for every eligible disabled individual. Through meetings with the individual, counselors determine the individual's potential, existing skills, and other resources. During this process, and throughout the rehabilitation, the program may provide a variety of services, including the following:

- A medical examination to determine the extent of one's disability, suitability for employment, and specific medical help needed.
- Counseling and guidance to determine the individual's rehabilitation potential, employment potential, and the type(s) of employment most suitable for him/her.
- Medical help to reduce or remove disability and improve or restore job performance. This help includes medical, surgical, psychiatric, and hospital services; artificial limbs, braces, hearing devices, and eyeglasses needed on the job.
- Job training at trade schools, rehabilitation centers, or at home.

- Educational opportunities, including payment of college tuition and fees and other educational expenses as necessary, if college is required for the individual to be able to earn a livelihood.

- Financial assistance during the rehabilitation period for room and board, transportation, and other necessary assistance.

- Referral and job placement.

- On-the-job help, if needed, including expenses related to getting to the job.

The federal government provides extensive support to the states for vocational rehabilitation services. However, the services themselves are very individualized, and information useful to the individual must be sought at the state and local, rather than the federal, level.

Federal Student Financial Aid

No specific federal financial aid program exists to enable disabled individuals to attend college except in cases when the vocational rehabilitation agency determines that a college education is a necessary component of job preparation. In these cases, financial assistance may be provided. There are, however, four kinds of federal financial aid programs available to all students in need:

- Grants given on the basis of financial need. Money received does not have to be repaid;

- Loans which must be repaid;

- Work-study programs which provide a part-time job;

- Benefits, such as GI Bill, Social Security, and Junior GI, which do not have to be repaid.

To learn more about the various federal student aid programs, see your high school guidance counselor or the financial aid officer at any college or vocational school, or contact:

Office of Student Financial Assistance
P.O. Box 84
Washington, DC 20044
(202) 472-5080

EMPLOYMENT

There are currently more than 2500 local Employment Security (ES) offices located throughout the United States. More commonly referred to as State Employment Services or State Job Services, these public employment centers exist to help employers find workers, and workers to find jobs. The ES is specifically responsible for helping disabled job seekers, with each office mandated by law to employ a specialist trained to work with disabled people, or to make referrals to other agencies.

For more information or for help in finding a job, look in the telephone directory under "employment services," which should refer you to the state agency responsible for the ES program in your area.

Federal Jobs

All federal jobs for regular appointment must be announced to the public and are filled on a competitive basis. A small number of special "A" appointment positions for disabled individuals, however, are not competitive under the following conditions:

- Mentally retarded individuals referred by their vocational rehabilitation counselor;
- Severely physically disabled individuals referred through their vocational rehabilitation counselor or taking a 700-hour trial appointment.

Federal Job Information Centers

For more information about federal employment possibilities, contact the nearest Federal Job Information Center. The Office of Personnel Management maintains 67 centers to provide federal job information and to assist applicants for federal employment, with special arrangements available for disabled individuals. Federal Job Information Centers are listed under "U.S. Government" in metropolitan area phone directories. Federal employment information will also be posted in all State Job Service agencies.

Several tests used in screening federal job applicants can be taken by a blind or visually impaired person in Braille, large type, or in recorded form. If a test is unavailable in any of these formats, the Job Information Center is required to provide reader assistance to insure that the same standards are used in screening all applicants.

In addition, all federal personnel offices employ selective placement coordinators who provide assistance to disabled individuals.

State Job Services

State, county, and local governments have their own civil service systems which can also be explored for possible job opportunities. In addition, most states have a Governor's Committee on Employment of the Handicapped which works with business and industry to open up job opportunities for disabled individuals.

Small Business

Disabled persons interested in going into business for themselves may qualify for federal assistance and low-cost loans from the Small Business Administration (SBA). If no listing appears in your phone book for an SBA office in your area, contact:Small Business Administration, Director, of Financing, 1441 L Street, N.W., Washington, D.C. 20416, (202) 653-6574

FINANCIAL ASSISTANCE

Two basic federal programs provide direct and continuing financial assistance to disabled persons; these include social security disability insurance benefits and supplemental security income.

Social Security Disability Insurance Benefits

Social Security disability insurance benefits may be paid to a disabled worker under 65 and his or her family when earnings are lost or reduced due to the worker's disability. Before a disabled worker and his or her family can get benefits, the worker must have credit for a certain amount of work under social security. The exact amount of work credit needed depends on the worker's age.

An individual may be considered "disabled" if a physical or mental impairment which prevents him/her from working and is expected to last for at least 12 months.

Monthly disability benefits can be paid to a disabled worker's:

1. Unmarried children under 18 (or under 22 if full-time students);
2. Unmarried children 18 or older who were severely disabled before 22 and continue to be disabled;
3. Wife or husband 62 or older;
4. Wife under 62 if she cares for the worker's child who is under 18 or disabled and receiving benefits based on the disabled worker's earnings.

NOTE: Children 18 or older who were disabled before 22 can also receive monthly benefits when either parent becomes entitled to retirement payments or dies after having worked long enough under social security. A disabled widow or widower, or a disabled surviving divorced wife 50 or older may be eligible for monthly survivors payments when a worker dies.

The people in any social security office will be glad to answer any questions. They also have a wide variety of publications, with single copies available free of charge. Local social security offices are listed in the telephone directory under "Social Security Administration."

Supplemental Security Income

Supplemental security income (SSI) makes monthly payments to aged, disabled, and blind people with limited income and resources. Disabled and blind children, as well as adults, may qualify for SSI payments. It makes no difference how young a person is.

To receive SSI payments on the basis of disability or blindness, you must meet the social security definition of "disabled" or "blind." However, social security work credits are not required to receive SSI payments. Individuals may be eligible for SSI even if they have never worked. In addition, people who receive SSI checks can receive social security checks, too, if they are eligible for both.

To be eligible for SSI, you must have limited income and resources, be a resident of the United States or Northern Mariana Islands, and be either a United States citizen or a lawfully admitted immigrant.

Not all income and resources are counted in determining eligibility for SSI. Generally, the first $20 a month of unearned income and the first $65 a month in earnings are not counted. Income above these levels usually reduces the amount of the basic SSI payment. A home and the land adjacent to it are not counted. Personal effects or household goods, a car, and life insurance policies may not count, depending on their value. The federal government does not put liens on recipients' homes.

States may add to the federal SSI payments. The states also provide Medicaid, food stamps, and various social and rehabilitation services.

For more information about SSI, contact your local social security office.

MEDICAL ASSISTANCE

The primary sources of federal medical assistance for disabled persons are Medicare and Medicaid; Crippled Children's Services; and the Early Periodic Screening, Diagnosis and Treatment Program.

Medicare

This health insurance program is designed to serve persons over 65 years of age and disabled persons under 65 years of age who:

1. have been entitled to receive Social Security disability benefits for a total of 24 months; or

2. who need dialysis treatments or a kidney transplant because of permanent kidney failure.

The medicare program, available regardless of financial need, has two parts:

Part A: Hospital insurance at no cost that helps pay for care while in the hospital and for related health care services after leaving the hospital.

Part B: Voluntary medical insurance at a monthly premium that helps pay doctor bills and other approved medical services.

More information about Medicare is available from your local social security office, or by contacting:

Health Care Financing Administration Inquiries Branch
Room 1-N-4
East Lowrise Building
6325 Security Boulevard
Baltimore, MD 21207
(301) 594-9622

Medicaid

Medicaid (Medical Assistance Programs) is a joint federal/state program providing physical and related health care services to persons with low incomes. Disabled persons may be eligible for Medicaid on the basis of their income. Each state establishes its own eligibility requirements for Medicaid.

Because eligibility is determined by your state program of public assistance (welfare) on the basis of broad federal guidelines, geographic differences exist between eligibility requirements and types of services covered. Generally, persons may be eligible for Medicaid if they are receiving welfare, other public assistance benefits, or supplemental security income, or are blind or disabled. Medicaid services are available in all states except Arizona.

Individuals with higher incomes may be eligible for Medicaid Supplemental Medical Care Assistance, or their children may be eligible if medical expenses exceed a given percentage of their annual income.

Further information on Medicaid and assistance in applying is available from your local or state welfare or public assistance office.

If you cannot get information locally, contact:

Health Care Financing Administration Inquiries Branch
Room 1-N-4
East Lowrise Building
6325 Security Boulevard
Baltimore, MD 21235
(301) 594-9622

Crippled Children's Services

Crippled Children's Services (CCS) is a joint federal/state program providing medical and related services to disabled children from birth to age 21.

All states must provide free medical diagnosis and evaluation for all disabled children. (No state residency period is required before such services are provided.) The range and cost of additional treatment or hospital care services vary from state to state. All programs accept third-party payments such as Medicaid, Blue Cross, Blue Shield and other medical insurance.

For further information on services and programs available to disabled children, contact the Office of Crippled Children's Services or the Maternal and Child Health Office for your state. A list of these offices is provided in Appendix C.

Early Periodic Screening, Diagnosis and Treatment Program (EPSDT)

The EPSDT program screens children from low-income families to identify health care needs and related services which may be necessary.

Children receiving state Aid to Families with Dependent Children benefits, and children whose parents or guardians are receiving Medicaid and/or local or state public assistance benefits, are eligible for EPSDT.

EPSDT programs vary from state to state and are administered by either state public assistance (welfare) or health departments.

For more information on EPSDT contact your physician, or state health department, maternal and child health section.

TRANSPORTATION

In recent years, the federal government has stepped up its efforts to make transportation systems more accessible to disabled travelers. New regulations have been passed and better information is now available to assist disabled individuals in planning trips and using public transportation systems. Barriers still exist, however, and those with physical disabilities must plan and prepare trips much more carefully than the average traveler.

Each United States airline has a national company policy on accessibility and individual services to disabled individuals. Because these policies vary from airline to airline, it is advisable to make any special needs as a disabled person known when reservations are made, and to inquire whether the airline provides the needed services.

For more information, contact the individual airline directly or write for the publication Access Travel for the Handicapped, a booklet on design features, facilities, and services at 220 airport terminals worldwide. This publication is available from:

Consumer Information Center
Pueblo, CO 81009

Also helpful is the publication, Access Travel: A Guide to Accessibility of Airport Terminals. Available from:

Architectural and Transportation Barriers Compliance Board
330 C Street, S.W.
Washington, DC 20202
(202) 245-1591

Amtrak, the country's major passenger rail system, is becoming more accessible to disabled individuals. This federally subsidized rail system has announced that it will add to its system only new cars fitted with special facilities for the disabled.

Information on accessibility of trains and stations and assistance available to disabled or elderly passengers may be obtained from an authorized travel agent or by calling Amtrak. Dial (800) 555-1212 to request the toll-free Amtrak number in your state.

Amtrak also has a brochure, Access Amtrak, for disabled travelers. To request copies, write:

Amtrak Public Affairs
400 North Capitol Street, N.W.
Washington, DC 20001
(202) 383-3860

CIVIL RIGHTS/LEGAL ASSISTANCE

Office for Civil Rights

A disabled person has rights guaranteed by law to education, employment, health care, welfare, and any other public or private services that receive federal assistance.

It is the responsibility of the Office for Civil Rights in the Department of Education and the Office for Civil Rights in the Department of Health and Human Services to enforce federal laws prohibiting discrimination against persons on the basis of race, color, national origin, sex, age, or mental and physical disabilities, and to investigate discrimination complaints brought by individuals under these statutes.

If you feel that your rights have been violated--because of your disability or your child's disability--by a hospital, school, or any other institution receiving federal assistance, write to the Office for Civil Rights of the Department of Education (ED) (about schools), and to the Department of Health and Human Services (HHS) (about hospitals, social services) in your region.

Region I (CT, ME, MA, NH, RI, VT)
Room 2403
JFK Federal Building
Boston, MA 02203
ED: (617) 223-6397
HHS: (617) 223-4408

Region II (NJ, NY, PR, VI)
26 Federal Plaza, Room 3312
New York, NY 10278
ED: (212) 264-5180
HHS: (212) 264-3313

Region III (DE, DC, MD, PA, VA, WV)
3535 Market Street, Room 6300
Philadelphia, PA 19101
ED: (215) 596-6787
HHS: (215) 596-1262

Region IV (AL, FL, GA, KY, MS, NC, SC, TN)
101 Marietta Street, 27th Floor
Atlanta, GA 30323
ED: (404) 221-2954
HHS: (404) 221-2779

Region V (IL, IN, MI, MN, OH, WI)
300 South Wacker Drive
Chicago, IL 60606
ED: (312) 353-2520
HHS: (312) 886-2300

Region VI (AR, LA, NM, OK, TX)
1200 Main Tower Building, Suite 2335
Dallas, TX 75202
ED: (214) 767-3951
HHS: (214) 767-4056

Region VII (IA, KS, MO, NE)
601 East 12th Street, Room 248
Kansas City, MO 64106
ED: (816) 374-2223
HHS: (816) 374-2156

Region VIII (CO, MT, ND, SD, UT, WY)
1961 Stout Street, Room 1194
Denver, CO 80294
ED: (303) 844-5695
HHS: (303) 844-2994

Region IX (AZ, CA, HI, NV, GU, Trust Territories, Pacific Islands, American Samoa)
50 United Nations Plaza, Room 322
San Francisco, CA 94102
ED: (415) 556-8586
HHS: (415) 556-8586

Region X (AK, ID, OR, WA)
2901 Third Avenue - MS/510
Seattle, WA 98121
ED: (206) 442-1922
HHS: (206) 442-0473

Administration on Developmental Disabilities

The Administration on Developmental Disabilities (ADD) is responsible for administering the Developmental Disabilities Act of 1984 (Public Law 98-527). This Act aims to maximize the independence, productivity and community integration of developmentally disabled persons by assisting states to assure that these individuals receive appropriate care and services. In addition, the Act ensures that each state has a system to plan, coordinate, monitor, and evaluate services to protect the legal and human rights of the developmentally disabled.

One of the priority areas of the Administration on Developmental Disabilities is the Protection and Advocacy Program. Each state has a system to protect and advocate the rights of persons with developmental disabilities. This system provides the authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of developmentally disabled individuals who are receiving treatment, services, or rehabilitation within the state. The program is independent from any agency providing such services.

The most common types of assistance relate to education, employment, transportation, vocational rehabilitation, medical services, abuse and neglect, housing, architectural barriers, and guardianship. A list of the Protection and Advocacy Programs for each state is given in Appendix D.

TAX BENEFITS

In the computation of income tax, the Internal Revenue Service allows many medical and dental expenses to be deducted from income (in this case, of the disabled individual or his/her parents). Deductible items include:

- Special equipment such as a motorized wheelchair.
- Special items and drugs such as desferal.
- The cost and repair of special equipment such as the infusion pump.
- Payments for the installation of special equipment in the home or similar improvements made for medical purposes, such as ramps or elevators. (If these improvements increase the value of the property, expenses incurred will only be deducted to the extent that they exceed the increase in property value.)

In addition, the IRS allows tax credits for the cost of disabled dependent or disabled spouse care. Payment to relatives providing this care can be included if the relative is not your dependent or your child under 19 years of age. For further information on tax credits and deductions, contact your local IRS Office.

HOUSING

Rent Assistance

Low-income families (including the disabled) may be eligible for housing assistance payments from the U.S. Department of Housing and Urban Development (HUD). Payments by HUD are made directly to the owners of rental units to make up the difference between the HUD-approved rental amount and the amount the tenant is required to pay. Tenants pay between 25 percent and 30 percent of their adjusted income (gross income less certain deductions and exceptions). Rental assistance payments under this arrangement are not considered additional income for the tenant who is also eligible for supplemental income payments from the Social Security Administration.

For further information on rent assistance or other housing programs benefiting the disabled, write to:

U.S. Department of Housing & Urban Development
Washington, DC 20410

Ask for a copy of Changing Environments for People with Disabilities, publication number HUD-600-H.

Architectural and Transportation Barriers Compliance Board

The Architectural Barriers Act of 1968 (Public Law 90-480) decreed that all buildings constructed, leased, or altered with federal funds since the passage of the Act must be accessible to disabled individuals.

The Architectural and Transportation Barriers Compliance Board (A&TBCB) is the federal agency created to enforce the standards. If you have a complaint about an inaccessible building or you would like to receive the A&TBCB's brochure, Access America: The Architectural Barriers Act and You, contact:

Architectural and Transportation
Barriers Compliance Board
330 C Street, S.W.
Washington, DC 20202
(202) 245-1591

APPENDIX A

STATE GENETIC SERVICE COORDINATORS

ALABAMA

Wayne H. Finley, M.D., Ph.D.
State Genetic Project Director
University of Alabama at Birmingham
University Station
Birmingham, AL 35294
(205) 934-4973

ALASKA

David A. Spence, M.D., M.P.H.
Chief, Section of Family Health
Alaska Department of Health
& Social Services
Division of Public Health
Health and Welfare Building
P.O. Box H-06B
Juneau, AK 99811
(907) 465-3100

ARIZONA

Frederick Hecht, M.D., Director
Southwest Biomedical Research Institute
6401 East Thomas Road
Scottsdale, AZ 85251
(602) 945-4363

ARKANSAS

Becky Butler, M.S.W.
Genetics Program Coordinator
Department of Pediatrics/512 B
University of Arkansas Medical
Sciences Campus
4301 West Markham
Little Rock, AR 72205
(501) 661-5994

CALIFORNIA

George C. Cunningham, M.D.
Chief, Genetic Disease Branch
Department of Health Services
2151 Berkeley Way, Annex 4
Berkeley, CA 94704
(415) 540-2534

COLORADO

Robert S. McCurdy, M.D., M.P.H.
Director of Medical Affairs and
Special Programs
Department of Health
4210 East 11th Avenue
Denver, CO 80220
(303) 331-8373

CONNECTICUT

Vijaya V. Bapat, M.D.
Chief, Maternal and Child
Health Section
Department of Health Services
150 Washington Street
Hartford, CT 06106
(203) 566-5601

DELAWARE

Barbara Jarrell Krausz, B.S.
Genetic Services and Newborn
Screening Manager
P.O. Box 637
Dover, DE 19903
(302) 736-4786

DISTRICT OF COLUMBIA

Jill F. Shuger, Sc.M.
Genetics Program Coordinator
Department of Human Services
Commission of Public Health
Bureau of Maternal and Child Health
1875 Connecticut Avenue, N.W.
Room 804-B
Washington, DC 20009
(202) 673-6697

FLORIDA

Mittie Moffett, R.N., M.S.
Program Administrator
Children's Medical Services
Regional Genetics Program
1317 Winewood Boulevard
Tallahassee, FL 32301
(904) 488-6005

GEORGIA

Mary S. Harris, Ph.D.
Genetics Program Director
Community Health Section
Department of Human Resources
878 Peachtree Street, N.E.
Room 109
Atlanta, GA 30309
(404) 894-5122

HAWAII

Janet Huff, R.N.
Department of Health
Crippled Children's Services Branch
741 Sunset Avenue
Honolulu, HI 96816
(808) 732-3197

IDAHO

Mary Jane Webb
Genetic Services Program Manager
Idaho Department of Health
& Welfare
Bureau of Laboratories
2220 Old Penitentiary Road
Boise, ID 83712
(208) 334-2235

ILLINOIS

Sydney Kling, R.N.
Administrator
Genetic Diseases Program
Division of Family Health
Illinois Department of Public Health
535 West Jefferson Street
Springfield, IL 62761
(217) 785-4522

INDIANA

F. John Meaney, Ph.D.
Chief, Genetic Diseases Section
Maternal & Child Health Division
State Board of Health
1330 West Michigan Street
Box 1964
Indianapolis, IN 46206-1964
(317) 633-0805

IOWA

Roger R. Chapman, M.S.W.
Director
Birth Defects Institute, Division
of Maternal and Child Health
Department of Health
Lucas State Office Building
Des Moines, IA 50319
(515) 281-6646

KANSAS

Carolyn K. Domingo, R.N., M.S.
Genetic Services Coordinator
Crippled & Chronically Ill
Children's Program
Department of Health and
Environment
Forbes Field #740
Topeka, KS 66620
(913) 862-9360 Ext. 400

KENTUCKY

John Webb
Genetic Program Coordinator
Department for Health Service
Division of Maternal and Child Health
275 East Main Street
Frankfort, KY 40621
(502) 564-4430

LOUISIANA

Charles Myers, Administrator
Genetic Diseases Program
Office of Preventive and Public
Health Services
Department of Health and Human
Resources
325 Loyola Avenue, Room 613
New Orleans, LA 70112
(504) 568-5075

MAINE

Mollie W. Jenckes, M.H.Sc.
Director, Genetics, Prenatal Care
and Injury Control
Department of Human Services
Bureau of Health
Division of Maternal and Child Health
State House Station 11
Augusta, ME 04333
(207) 289-3311

MARYLAND

Susan R. Panny, M.D., Chief
Division of Hereditary Disorders
Maryland Department of Health and
Mental Hygiene
P.O. Box 13528
201 West Preston Street
Baltimore, MD 21201
(301) 225-6730

MASSACHUSETTS

Sharon E. Reid, M.S., Director
Genetics Program
Massachusetts Department of
Public Health
Division of Family Health Services
150 Tremont Street
Boston, MA 02111
(617) 727-0944

MICHIGAN

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Lansing, MI 48909
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MINNESOTA

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Minnesota Department of Health
717 Delaware, S.E.
Minneapolis, MN 55446
(612) 623-5269

MISSISSIPPI

Daniel R. Bender, Director
Mississippi Genetic Screening Program
Mississippi Department of Health
P.O. Box 1700
Jackson, MS 39215-1700
(601) 982-6571

MISSOURI

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Program Coordinator
Missouri Genetic Disease Program
Missouri Department of Health
P.O. Box 570
1730 East Elm Street
Jefferson City, MO 65102
(314) 751-8157

MONTANA

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Chairman, Department of Medical Genetics
Shodair Children's Hospital
840 Helena Avenue
P.O. Box 5539
Helena, MT 59601
(406) 442-1980

NEBRASKA

J. Douglas Campbell
Director, Bureau of Medical Services and Grants
Birth Defects Prevention Program
Nebraska Department of Health
301 Centennial Mall South
P.O. Box 95007
Lincoln, NE 68509
(402) 471-2647

NEVADA

Richard C. Bentinck, M.D., Chief
Bureau of Community Health Services
Nevada Division of Health
505 East King Street, Room 205
Carson City, NV 89710
(702) 885-4880

NEW HAMPSHIRE

Carol L. Struckmeyer, M.S.
Genetic Services Program
Bureau of Special Medical Services
Health and Human Services Building
6 Hazen Drive
Concord, NH 03301-6527
(603) 271-4533

NEW JERSEY

Doris S. Kramer, M.S.
Coordinator, Genetic Services Program
Prevention Services
Special Child Health Services Program
New Jersey Department of Health
120 South Stockton Street
CN 364
Trenton, NJ 08625
(609) 984-0775

NEW MEXICO

Jeffrey M. Davis, M.D., M.P.H.
Chief, Maternal and Child Health Bureau
New Mexico Health and Environment Department
P.O. Box 968
Santa Fe, NM 87504-0968
(505) 827-0020

NEW YORK

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Genetic Project Coordinator
Department of Health
1308 Empire State Plaza Tower Building
Albany, NY 12237
(518) 474-2050

NORTH CAROLINA

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Director Genetics Program
Division of Health Services
Department of Human Resources
P.O. Box 2091
Raleigh, NC 27602
(919) 733-7437

NORTH DAKOTA

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Department of Pediatrics
University of North Dakota Medical School
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Grand Forks, ND 58201
(701) 777-4277

OHIO

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246 North High Street
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OKLAHOMA

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Oklahoma City, OK 73152
(405) 271-4471

OREGON

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Portland, OR 97201
(503) 225-7703

PENNSYLVANIA

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Director, Genetic Diseases, Testing and Counseling Program
Division of Maternal and Child Health
Pennsylvania Department of Health
P.O. Box 90
Harrisburg, PA 17108
(717) 787-7440

PUERTO RICO

Pedro J. Santiago-Borrero, M.D.
Director, Genetic Diseases Screening Program
University Children's Hospital
University of Puerto Rico Medical School
G.P.O. Box 5067
San Juan, PR 00936
(809) 765-2363

RHODE ISLAND

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Division of Family Health
Department of Health
75 Davis Street, Room 302
Providence, RI 02908
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SOUTH CAROLINA

Robert H. Buchanan, Jr.
Deputy Director
South Carolina Department of Health
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Division of Children's Health
Bureau of Maternal and Child Health
2600 Bull Street
Columbia, SC 29201
(803) 758-5491

SOUTH DAKOTA

Virginia P. Johnson, M.D.
Director, Birth Defects Genetics Center
University of South Dakota
School of Medicine
414 East Clark Street
Vermillion, SD 57069
(605) 677-5623

TENNESSEE

Joan Furman Seaborg, R.N., M.S.N.
Director of Center Based Programs
Perinatal/Genetics
Maternal and Child Health Section
Department of Health and Environment
100 Ninth Avenue North
Nashville, TN 37219
(615) 741-7335

TEXAS

Gilbert Levine, M.D., Director
Division of Maternal and Child Health
Texas Department of Health
1100 West 49th Street
Austin, TX 78756
(512) 458-7700

UTAH

John C. Carey, M.D., M.P.H.
Department of Pediatrics
Division of Medical Genetics
University of Utah Medical Center
50 North Medical Drive
Salt Lake City, UT 84132
(801) 581-8943

VERMONT

H. Eugene Hoyme, M.D.
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University of Vermont
College of Medicine
A115 Medical Alumni Building
Burlington, VT 05405
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VIRGINIA

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Genetics Program Director
Bureau of Maternal and Child Health,
Virginia Department of Health
109 Governor Street
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(804) 786-7367

WASHINGTON

Roberta Spiro, M.S.
Health Services Administrator
Genetics Services Section
Department of Social and Health Services
1704 N.E. 150th Street
Seattle, WA 98155
(206) 545-6783

WEST VIRGINIA

West Virginia University Medical School
Morgantown, WV 26506
(304) 293-4451

WISCONSIN

Raymond Kessel, Ph.D.
Statewide Genetics Services Network
104 Genetics Building
445 Henry Mall
University of Wisconsin
Madison, WI 53706
(608) 263-6355

WYOMING

R. L. Meuli, M.D.
Director, Family Health Program
Division of Health and Medical Services
Hathaway Building, Fourth Floor
Cheyenne, WY 82002
(307) 777-6297

APPENDIX B

SELECTED SELF-HELP AND ADVOCACY GROUPS

A number of organizations may be able to provide educational materials, and contact with parents and concerned health professionals. Listed below are Cooley's anemia organizations as well as other groups that provide information on a broad range of topics related to chronic illness.

COOLEY'S ANEMIA ORGANIZATIONS

AHEPA COOLEY'S ANEMIA FOUNDATION
136-56 39th Avenue
Flushing, NY 11354
(718) 961-3666
Stephen S. Scopas, Chairman

1707 L Street, N.W.
Washington, DC 20036
(202) 628-4974
Timothy J. Maniatis, Executive Director

COOLEY'S ANEMIA FOUNDATION, INC.
105 East 22nd Street, Suite 911
New York, NY 10010
(212) 598-0911
(800) 221-3571
Michael C. DiFilippo, Executive Director

Suffolk County Chapter
James Broderick, President
2364 Middle Country Road
Centereach, NY 11720
(516) 981-5623

Long Island Chapter
Lawrence Rosano, President
215-06 29th Avenue
Bayside, NY 11360
(718) 423-3422

Ficarra-Caltabiano Chapter
Alfred Addessi, President
2550 Benson Avenue
Brooklyn, NY 11214
(718) 946-8322

Staten Island Chapter
Cammi Brandafino, President
60 Josephine Street
Staten Island, NY 10314
(718) 761-6482

Manhattan Chapter
Bapu Kamble, President
4055 Carpenter Avenue
Bronx, NY 10461
(212) 547-5842

Western New York Chapter
Joni LoCurto, President
93 Wellington Road
Buffalo, NY 14216
(716) 832-3055

Rochester Chapter
Michael LaComba, President
1 Great Oak Lane
Pittsford, NY 14534
(716) 342-0389

Tri-City Chapter
Anthony Genovese, President
29 Carrol Avenue
Albany, NY 12203
(518) 489-7703

Cooley's Anemia Volunteers, Inc. of New Jersey
Sandra Brady, President
275 Lexington Avenue
Jersey City, NJ 07304
(201) 332-5625

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Southern California Chapter
Charles Cavalieri, M.D., President
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GENERAL ORGANIZATIONS

COUNCIL FOR EXCEPTIONAL CHILDREN
1920 Association Drive
Reston, VA 22091
(703) 620-3660
Jeptha Greer, Executive Director

The Council attempts to advance the education of exceptional children and youth of the United States and Canada, whether gifted, retarded, impaired, or disabled. A publications catalogue is available upon request.

MARCH OF DIMES BIRTH DEFECTS FOUNDATION
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100
Charles L. Massey, President

Prevention of birth defects has been the goal of the March of Dimes for more than twenty-five years. Many publications are available for professionals and the general public. Contact your local chapter for a publications catalogue.

THE NATIONAL EASTER SEAL SOCIETY
2023 West Odgen Avenue
Chicago, IL 60612
(312) 243-8400
John Garrison, Executive Director

The Society is concerned with advocacy, public health education, research, and providing grants for investigation into the causes of disabled people. A publications catalogue is available on request.

NATIONAL GENETICS FOUNDATION, INC.
555 West 57th Street
New York, NY 10019
(212) 586-5800
Ruth Y. Berini, Executive Director

The Foundation develops and implements delivery systems to incorporate clinical genetics advances into health care for use in diagnosis, treatment, prevention and counseling for genetic disorders. Publications include Can Genetic Counseling Help You? and For the Concerned Couple Planning A Family.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC. (NORD)
P.O. Box 8923
New Fairfield, CT 06812
(203) 746-6518
Abbey Meyers, Executive Director

This organization is a coalition of voluntary health agencies, medical researchers and private citizens dedicated to the interests of individuals with rare disorders.

NATIONAL SELF-HELP CLEARINGHOUSE
33 West 42nd Street
New York, NY 10036
(212) 840-1259
Frank Riessman, Executive Director

The Clearinghouse can provide information about self-help groups in your area, as well as books and pamphlets on how to start a group of your own and what to look for in a group you join.

PARENTS HELPING PARENTS
505 Race Street
San Jose, CA 95116
(408) 272-4774
Florene Poyadue, Executive Director

This organization is a network of parents of children with mental and physical disabilities. Bibliographies and information packets covering a wide range of disabilities are available.

APPENDIX C

State Directors of Maternal and Child Health and Crippled Children's Services

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APPENDIX D

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APPENDIX F

GLOSSARY

amniotic sac - The membranes within the uterus containing fluid and the fetus.

alpha globin chain - One of the chains of amino acids in hemoglobin; each normal hemoglobin molecule in an adult contains two alpha globin chains and two beta globin chains.

beta globin chain - Another chain of amino acids in hemoglobin; each normal hemoglobin molecule in an adult contains two beta globin chains and two alpha globin chains.

blood typing and cross-matching - Before a transfusion can be given, the type of blood from both donor and recipient must be determined. The two major blood groups are ABO and Rh. Donor's blood compatible with that of the patient (recipient) must then be cross-matched by mixing the donor's red blood cells with a sample of the recipient's serum and vice versa. If the cells in these mixtures do not clump, the transfusion may be administered without fear of an immediate adverse reaction.

bone marrow - The tissue in the interior cavities of bones that produces the cells of the blood.

carrier - A person whose chromosomes contain, or "carry," both an abnormal gene for a trait, (which is not generally expressed) and a normal gene for the same trait. Some abnormal genes can be detected by laboratory tests.

chromosomes - Linear structures in the cell nucleus that contain the genes.

Cooley's anemia - The commonly used name for beta thalassemia major, also called "Mediterranean anemia."

DNA (deoxyribonucleic acid) - A chromosomal constituent of the nuclei of living cells that consists of a long chain of paired nucleotide bases joined by hydrogen bonds and twisted into a double helix; its sequence determines an individual's inherited characteristics.

endocrine glands - The glands or organs, such as the thyroid gland, adrenal glands, and the pancreas, that produce specific substances (hormones) secreted directly into the blood or lymph and which act upon other organs. Improperly functioning endocrine glands may cause grave disorders or death.

fetus - The developing being in the uterus eight weeks after conception until birth. From conception to eight weeks of age, the term embryo is used.

gene - A self-reproducing segment of DNA that makes up a unit of heredity and is located in a definite position (locus) on a particular chromosome. The gene is responsible for the transmission of an inherited characteristic or condition from parents to their children.

hemoglobin - The protein pigment of the red blood cells that carries oxygen to the tissues. Hemoglobin is made up of two parts: heme, which contains iron, and globin chains.

hemoglobin A - The normally predominant type of hemoglobin in the adult; it is either absent or reduced in amount in Cooley's anemia.

hemoglobin A_2 - A type of hemoglobin present in only limited amounts in the red blood cells of the adult; it is usually increased in amount in beta thalassemia minor.

hemoglobin F - Normally the predominant type of hemoglobin in the fetus and the newborn, it persists in very small amounts after the normal switch to hemoglobin A has taken place, but is increased in amount in Cooley's anemia.

hormone - A chemical substance, produced in the body, that has a specific effect on the activity of a particular gland or organ.

iron chelator - A chemical or drug that combines with iron and thus enables the body to eliminate the metal. The drug deferoxamine is the iron chelator used to remove the damaging excess iron stored in vital organs as a consequence of the frequent blood transfusions used in the treatment of patients with Cooley's anemia.

platelets - Small cells without nuclei that circulate in the blood and aid in the coagulation of the blood and in the contraction of blood clots.

pneumococci - Virulent bacteria (Diplococcus pneumoniae) that cause lobar pneumonia; they may also cause a serious infection in the blood stream in patients whose immune functions are impaired and who are thus highly susceptible to infections.

red blood cells (erythrocytes) - Cells of the blood that contain hemoglobin and function chiefly to transport oxygen to tissues and organs of the body.

RNA (ribonucleic acid) - A constituent of all living cells consisting of a single-stranded chain of nucleotide bases and the sugar ribose. There are many forms of RNA, including messenger RNA, transfer RNA and ribosomal RNA, all of which are involved in protein synthesis. Messenger RNA is decreased in amount in the Cooley's anemia patient, accounting for the inability of the red blood cells to produce a sufficient amount of hemoglobin A.

stem cell - An early, less differentiated form of cell, found mostly in the bone marrow, from which the highly specialized cells of the blood descend.

thalassemia - A group of inherited anemias resulting from an insufficient production of either the beta or alpha globin chains of hemoglobin. Beta thalassemia major and minor are the forms most commonly recognized in the United States, while alpha thalassemia is commonly found in the Far East.

white blood cells (leukocytes) - Unpigmented cells of the blood concerned chiefly with defending the body from infection.

NOTES